

Caring for a Patient with Schizophrenia

Ethnic/Racial Differences in the Experience of Shame

caregivers | culture | distress | emotion | families | family | psychosis | research | schizophrenia | shame | web-only feature

Drs. de Mamani and Suro recently published an article titled “The effect of a culturally informed therapy on self-conscious emotions and burden in caregivers of patients with schizophrenia: A randomized clinical trial” in *Psychotherapy*.

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Schizophrenia is a disabling, chronic psychiatric disorder that occurs in approximately 1% of the population (Goldner, Hsu, Waraich & Somers, 2002; Mueser & Jeste, 2008). It has severe consequences for patients with the disorder, as well as their caregivers who often present with high levels of psychological distress (Awad & Voruganti, 2008). In addition to the day-to-day stress of caring for someone with a severe mental illness, caregivers of patients with schizophrenia often experience high levels of self-conscious emotions such as shame.

In the context of a larger randomized control trial, we uncovered ethnic/racial differences in the experience of shame for schizophrenia caregivers. The overarching aim of the study was to test whether a family-focused, culturally-informed treatment for schizophrenia (CIT-S) was effective in lowering distress for caregivers of patients with this illness (see [Weisman de Mamani and Suro, 2016](#)). The study also attempted to assess

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whether changes in three specific variables (shame, guilt and interdependence) might account for some of the therapeutic benefits of this intervention. Over the course of our analyses, we became interested in a finding that was not central to our broader study questions, but is fascinating and has significant clinical implications in the field of caregiver well-being.

The self-conscious emotion of shame has been found to have a direct impact on caregiving [outcomes](#) for family members of patients with schizophrenia as well as indirect implications for the patients themselves (Teschinsky, 2000).

Historically, parents have carried the responsibility for the onset of their offspring's schizophrenia (Jones, Kugler & Adams, 1995). This misconception has contributed to increased experiences of shame as well as avoidance of treatment, in part, for fear of stigmatization (Winefield & Burnett, 1996).

Shame has been found to be associated with:

- more generalized psychological distress (Tangney, 1995), and
- critical, hostile coping responses that are more likely to correspond with unhelpful communication and behaviors that may exacerbate the patient's symptomology and course of illness (Conradt, Dierk, Schlumberger, Rauh & Hebebrand, 2008; Jenkins & Karno, 1992).

There is little research examining ethnic/racial differences in the experience of shame related to caring for a patient with schizophrenia. However, there is a strong body of work demonstrating that African-American and Hispanic caregivers appraise the act of caregiving as more normative and less burdensome than do Caucasian caregivers and, consequently, exhibit lower levels of poor mental health as a result of caregiving (e.g. Haley, Roth & Coleton, 1996; Lawton, Rajagopal, Brody, & Kleban, 1992; Magaña et al., 2007).

Caregiver Participant Demographics

Participants in this study were caregivers of a patient with schizophrenia. The sample included 113 participants (71 female, 42 male) with a mean age of 53.77 years ($SD = 14.93$), comprising 66 families. The average number of caregivers per family was 1.72. Sixty percent of the family member sample identified as Hispanic, 28.2% as Caucasian, 8% as [African American](#) and 3.8% identified as "Other." Seventy-two percent of the assessments took place in English, 28% were conducted in Spanish.

SELF-CONSCIOUS EMOTIONS FOR SCHIZOPHRENIA SCALE

Weisman de Mamani's (2007) *Self-conscious Emotions for Schizophrenia Scale* assessed shame about having a relative with schizophrenia. Relatives reported the degree to which having a relative with schizophrenia is a source of shame to them. Responses ranged from 1 (Not at all true) to 7 (Very true), with higher scores reflecting a greater degree of the self-conscious emotion in question. Ethnicity was measured using a demographics questionnaire.

Results

One-way ANOVA's were used to assess any significant relationships between shame and ethnicity. Significant ethnic differences were found for levels of shame regarding having a relative with schizophrenia ($F = 7.07, p < .01$).

Specifically, African American caregivers demonstrated significantly higher levels of shame when compared with Caucasians.

Hispanics did not significantly differ from African Americans nor Caucasians.

Discussion

Our results indicated that African American caregivers endorsed higher levels of shame than other ethnic groups in this sample. Interestingly, this was not necessarily an anticipated finding, because as previously noted, members of ethnic/racial minority groups have been demonstrated to endorse caregiving as more normative than Caucasian caregivers.

However, research in the area of racial identity may shed light on this finding. Steele and Aronson, 1995 indicate that, due to the often chronic and constant exposure to society's negative messages, African Americans are more likely than other racial groups to internalize a sense of inferiority.

Subsequently, as a group African Americans may be more prone to feeling shame than other racial groups when confronted with serious mental illness in the family.

Perhaps these higher levels of shame are also a reflection of ethnic/racial differences in perceptions of severe mental illness. Research has indicated that African Americans may hold more stigmatizing views of mental illness,

particularly schizophrenia (Anglin et al., 2006). For example, Whaley (1997) found that African Americans were more likely than other racial/ethnic groups to associate severe mental illness with a heightened risk of violence and danger. It is possible that feelings of stigma related to having a loved one with a severe mental illness may vary according to racial/ethnic group and thus contribute to levels of shame experienced by caregivers.

It will be important for future research to clarify the mechanisms that may account for higher levels of shame for African American caregivers when confronted with a loved one with schizophrenia. As noted, high levels of shame among caregivers is associated with increased psychological distress for family members and has indirect implications for patients as well.

It would be beneficial for subsequent studies to investigate the underlying cognitions and perceptions that may be contributing to increased shame. This may entail examination of broader constructs such as racial identity as well as more specific perceptions of stigma associated with schizophrenia as an illness.

Clinical Recommendations

Some recommendations for therapists working with African Americans and other caregivers of a loved one diagnosed with schizophrenia include:

- Addressing the role of caregiver shame by **exploring how perceptions of self have been impacted by caring for a family member with schizophrenia**. When working with African American caregivers, it is important to keep in mind the broader societal and historic factors that may contribute to a generalized predisposition to shame.
- **Attending to the stigma that is often attached to a diagnosis of schizophrenia** by providing psychoeducation on the role of genetic predisposition as well as the stress-vulnerability model of the illness. This may be particularly relevant for African American families who, as an ethnic group, may be likely to endorse increased levels of shame.
- Exploring the effect of caregiver burden and how activities of caregiving have impacted external stress as well as internal well-being. Problem-solving strategies may be used to reduce external stress when possible and increase self-care behaviors. **Incorporation of the family's endorsed spiritual or religious values may be incorporated as well to improve psychological well-being.**
- **Providing positive reinforcement for the ways that the family member may finding meaning or a sense of pride in their role as a caregiver.** This may be especially relevant for African American caregivers who are more likely than non-minority caregivers to endorse caregiving as a culturally normative.

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